



Κλινική Ρευματολογίας, Κλινικής Ανοσολογίας και Αλλεργίας ΠΑΓΝΗ

Η κοορτή ΣΕΛ «Λητώ»

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(Αντώνης Φανουριάκης)



“Leto” SLE Registry Establishment objectives

•To estimate the **incidence and prevalence** of systemic lupus erythematosus (SLE) in Crete between 1999-2014.

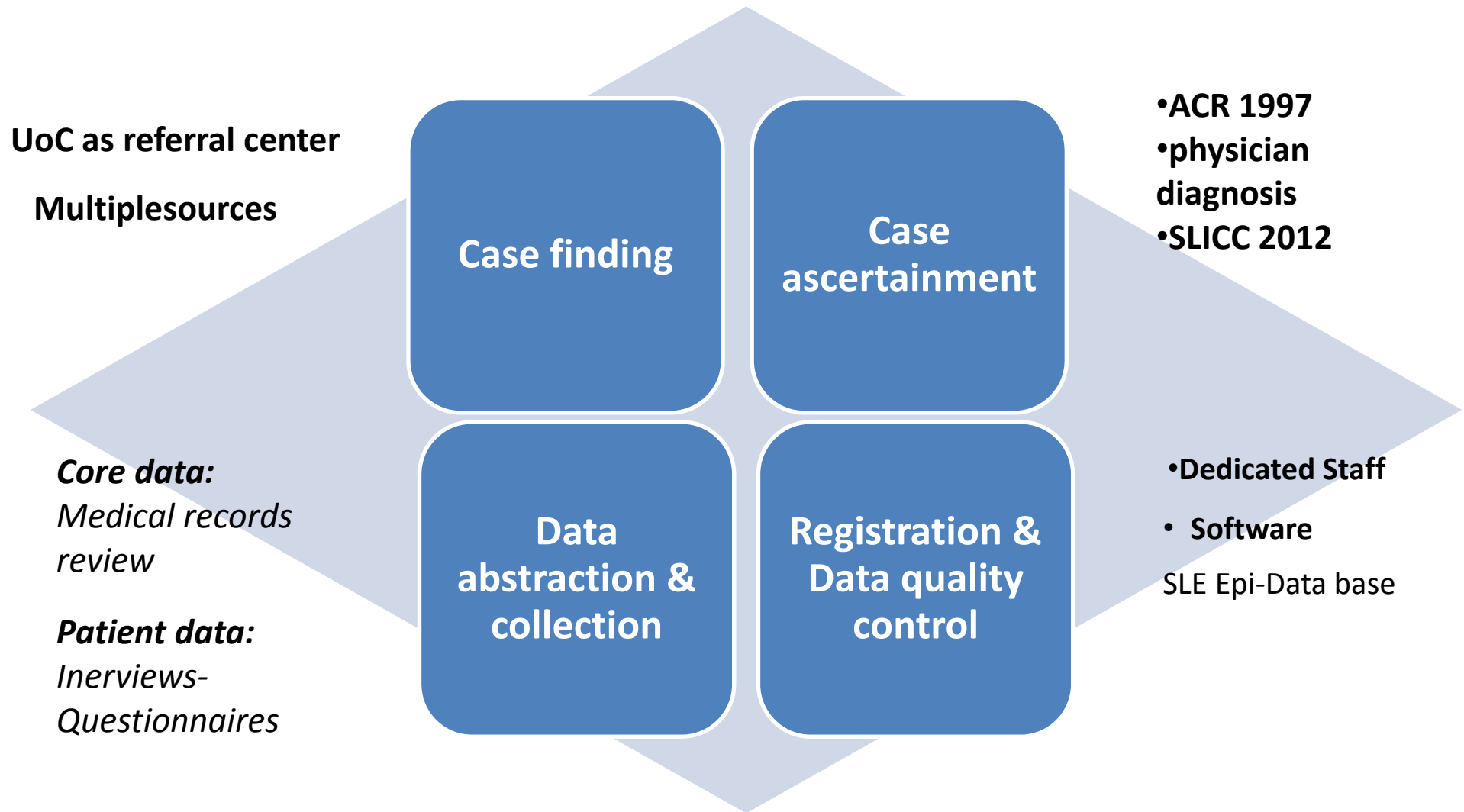
•To describe the disease burben and examine how **environmental or health related lifestyle factors** (urbanicity, smoking, pesticides etc) effect SLE progression and outcomes.

The screenshot displays the 'Leto' SLE Registry software interface. At the top, there is a title bar 'Αρχική Καρτέλα Ασθενή'. Below it, there are input fields for 'ID Ασθενούς' (16), 'AM' (2100057382), 'ΑΜΚΑ' (13), and 'Ταυτοποίηση Φακέλου' (checked). The 'Θέση Φακέλου' is set to 'ΑΡΧΕΙΟ ΣΕΛ'. The patient's name is 'Αρ. Ζαχαρίας Τζαμάρης'. The gender is 'Female', and the birth date is '13 / 4 / 1980'. The primary diagnosis is 'Αδιαφοροποίητο Νόσημα Συνδετικού Ιστού'. The interface includes tabs for 'Σχόλια-Επιλογές', 'Δημογραφικά', 'Ρευματολογικά Νοσήματα', 'Πρωτόκολλα', 'Επισκέψεις', and 'Επιλογές SLE Cohort'. A 'Patient Data' section contains buttons for 'Καρτέλα Κριτηρίων', 'Δίκτης Βλάβης', 'SLEDAI2K', 'Inclusion Criteria', 'Surgical Hx', 'Demographics', 'Preventive', 'Lifestyle - Work', 'GOB', 'Family History', 'Manifestations', 'Comorbidities', 'Health Care Use', and 'Mental Health'.

Target population

- ✓ southernmost Mediterranean island
- ✓ 0,6 milion people
- ✓ genetically homogenous
- ✓ mixed urban-rural

Leto SLE registry: Methodology



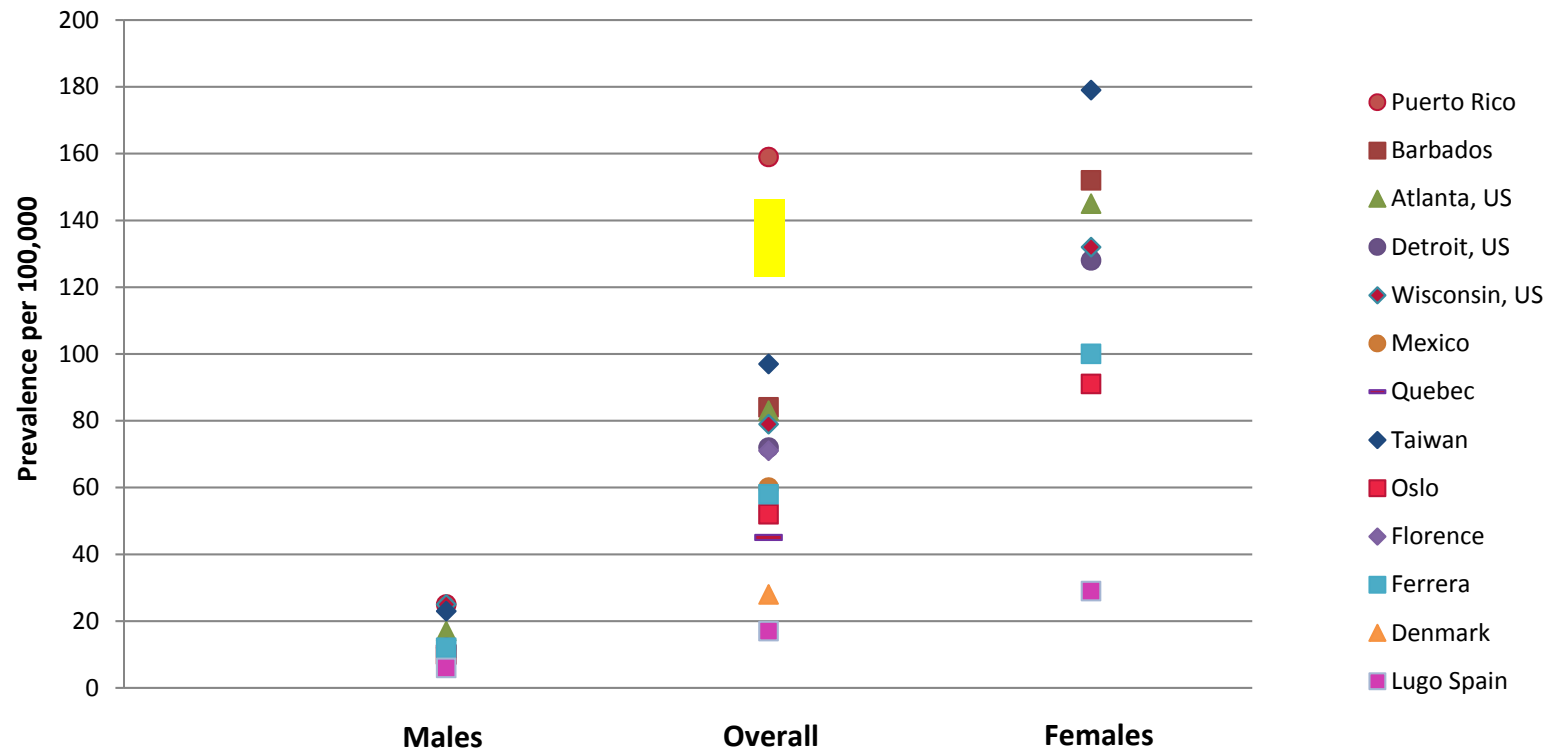
Funding: "Aristeia I"

How common is SLE?

SLE prevalence in Greece

%	Location	Time Period	Reference
0.149 %	Crete	1999-2014	Gergianaki et al. <i>Ann Rheum Dis</i> 2015;74 (Suppl2): 1275
0.075%	National	2014	Sfikakis et al. <i>Ann Rheum Dis</i> 2015;74(Suppl2): 790
0.038 %	Northwest	1985-2001	Alamanos et al. <i>J Rheumatol</i> 2003;30;731-735
0.110 %	Central	2010	<i>Anagnostopoulos et al. BMC Musc Dis</i> 2010, 11:98
0.005%	Mainland	2003	Andrianakos et al. <i>J.Rheumatol.</i> 2003;30:1589–601

SLE prevalence worldwide



SLE Incidence (new dx/year)

1999-2001	2002-2004	2005-2007	2008-2010	2011-2013
3.0 (SD ± 0,6)	8 (SD ± 2)	10 (SD ± 4)	12.5 (SD ± 0,6)	12 (SD ± 1,76)

¶1999-2013 mean annual incidence in Southernmost Crete island 9/10⁵

¶ Leto Registry

Table 3. New cases of SLE per 5 years over the period 1982–2001. Data are mean annual incidence rates per 100,000 inhabitants (95% CI).

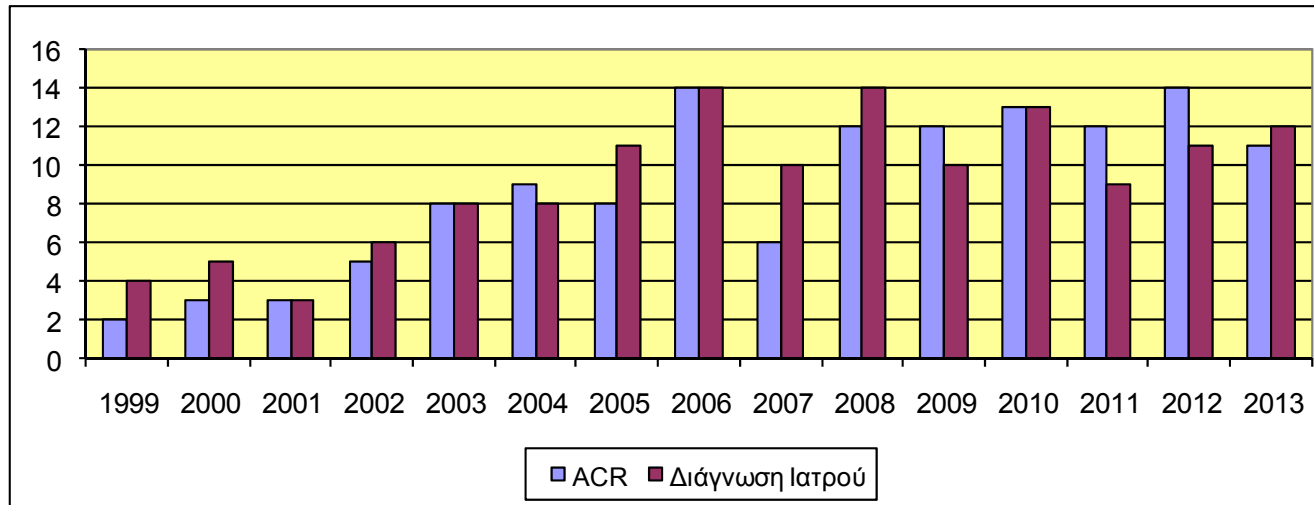
	1982–86	1987–91	1992–96	1997–2001	p*
Men	0.45 (0.39–0.51)	0.60 (0.55–0.65)	0.25 (0.20–0.30)	0.49 (0.45–0.53)	NS
Women	2.21 (1.62–2.80)	3.12 (2.57–3.67)	3.24 (2.72–3.76)	3.67 (3.16–4.18)	< 0.05
Total	1.37 (0.95–1.79)	1.88 (1.46–2.30)	1.79 (1.38–2.20)	2.10 (1.69–2.51)	< 0.05
Age adjusted	1.41 (0.99–1.83)	1.95 (1.04–2.72)	1.86 (1.45–2.27)	2.19 (1.78–2.60)	< 0.05

*According to chi-square — trends in proportion. NS: not statistically significant.

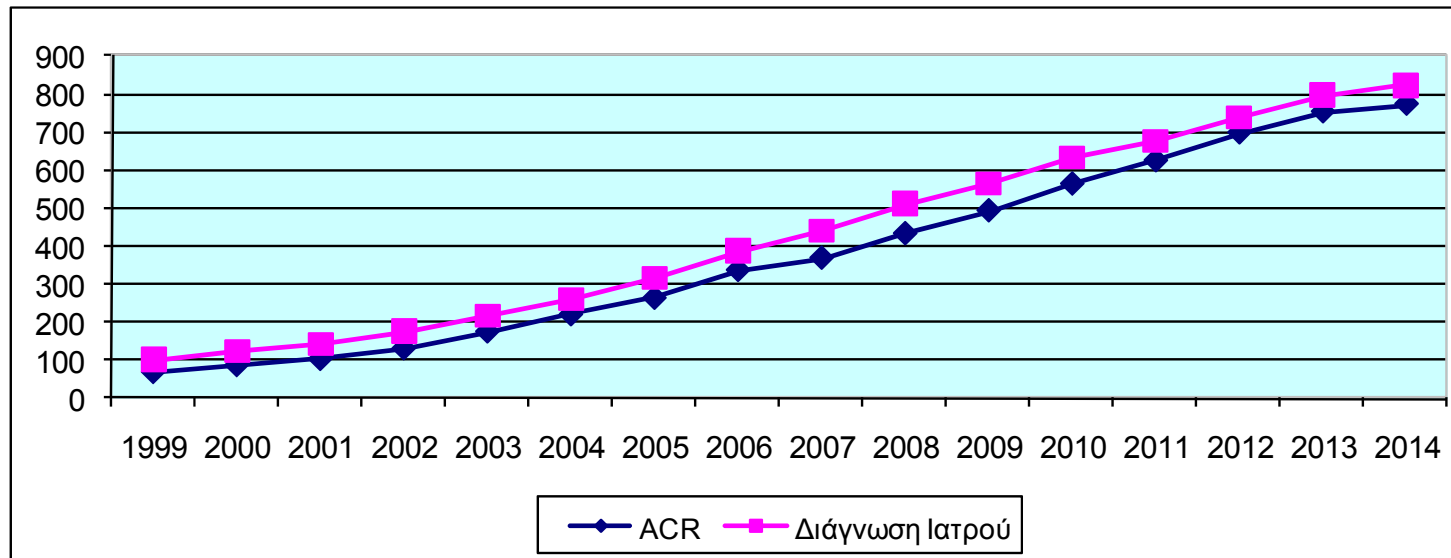
* 1982-2001 mean annual incidence in North West Greece 1,9/ 10⁵

SLE occurrence trends ¶

New dx/10⁵



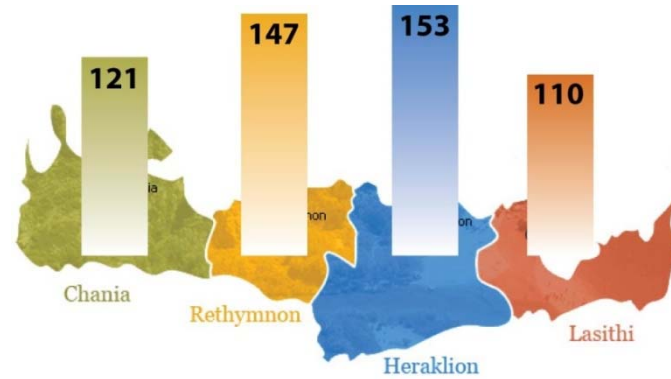
Patient Number



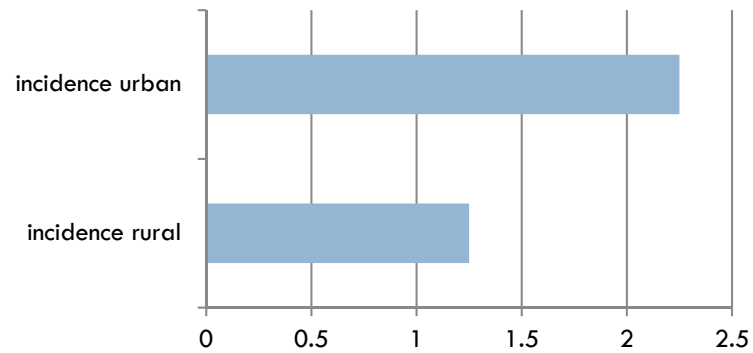
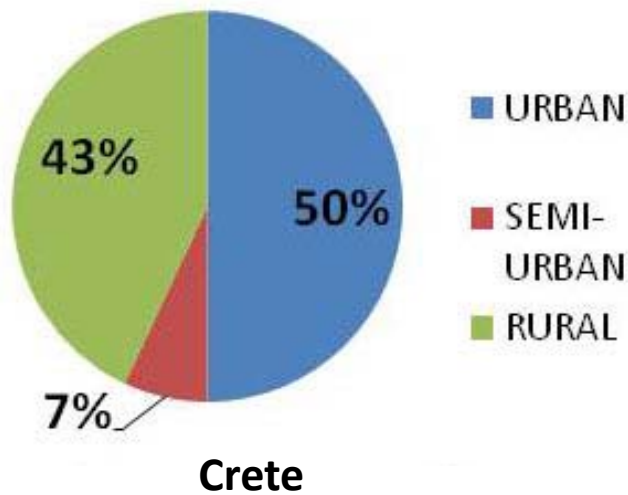
Geographic variability

*Crete Island

Urban (>15,000 habitants 39%)
 Semiurban (10,000-15,00008%)
 Rural (<10,000 53%).



Both prevalence and incidence higher in urban population



Ioannina

Is SLE different in Greece?

Key demographic characteristics

Gender (female/male)	13:1
Nationality, Cretan %	97
Descent, Cretan %	80
Marital status, married %	81
Education (<12 years) %	70

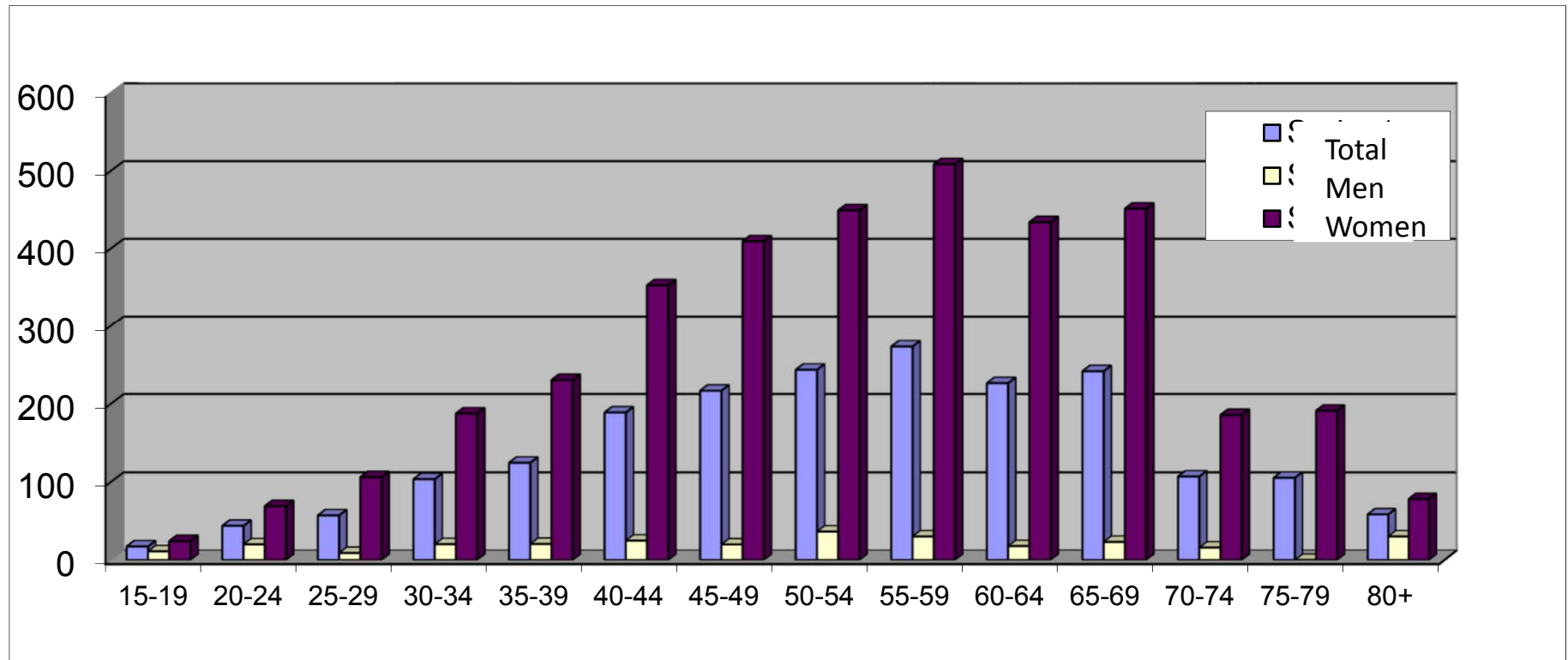
Obesity (BMI>30 %)	30
Smoking, active %	30
Pesticides%	30

Leto Registry (*n*=733 [*n*=328 regular f/u)

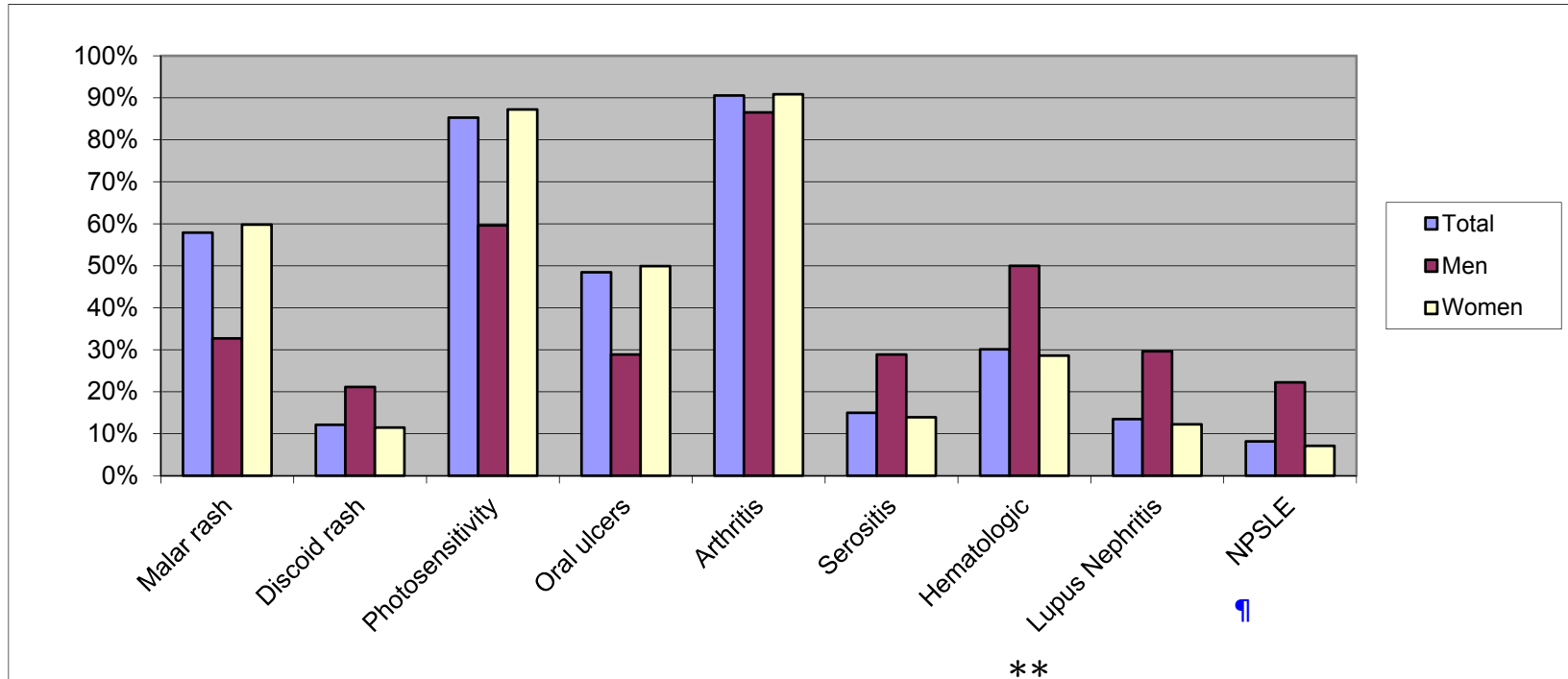
(*n*= 323 pt questionnaires)

	Cretan Cohort yrs, mean (\pm SD)	Ioannina Cohort yrs, mean (\pm SD)
Age at diagnosis	43 \pm 15	38.83 (18.02)

Age-distribution in SLE prevalent cases



Clinical manifestations



	Ioannina Cohort	Cretan Cohort
Photosensitivity, %	51.1	85
Butterfly rash, n (%)	66.3	58
Arthritis, n (%)	50	91
Serositis, n (%)	11.2	15
Nephritis	15	13,5
Antinuclear antibodies, n (%)	86	84
anti- DNA, n (%)	44.4	23
Anti-Smith antibodies, n (%)	10.7	14

****biopsy-proven nephritis
13.5%**

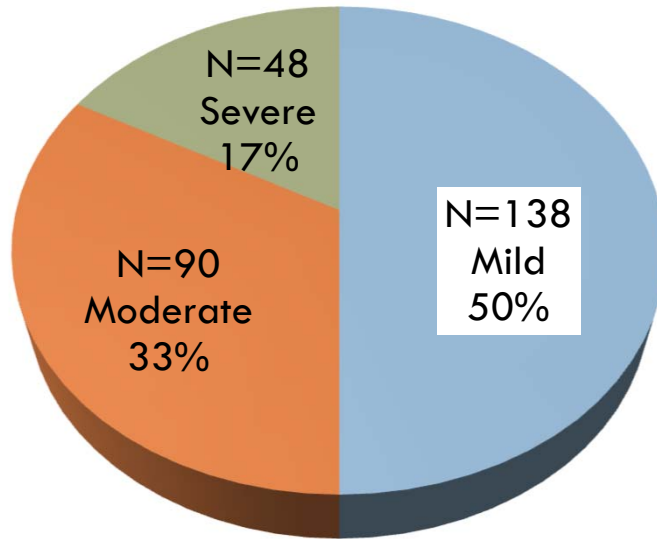
**¶ (1ary NPSLE) attributed to
SLE 8%**

Lupus Nephritis Epidemiology ¶

- Prevalence 20/100.000 (n=104)
- 13,5 % of total SLE cases
- 30% of men vs 12% of women patients with SLE has nephritis
- Non Reversible Renal Damage in SLE nephritis patients

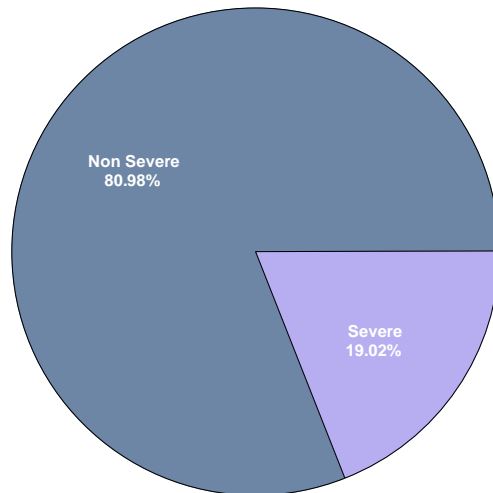
•Total	19%	
•GFR<50	6%	
•PROTEINURIA> 3.5/24h	6%	
•ESRD	8%	

SLE Severity in Greek patients



**Leto Registry n=276
(Physician based)**

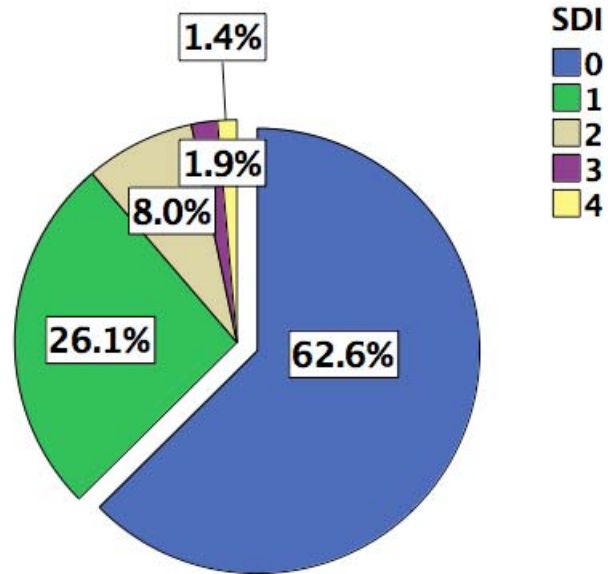
Substudy



LyCossubstudy: proportion of severe vs. non-severe patients (3months period, 2011)

**** Involvement of renal, neurological, cardiovascular or respiratory organs over the last 6 months AND Corticosteroids >7.5 mg/day OR antimalarial(s) OR immunosuppressant(s)**

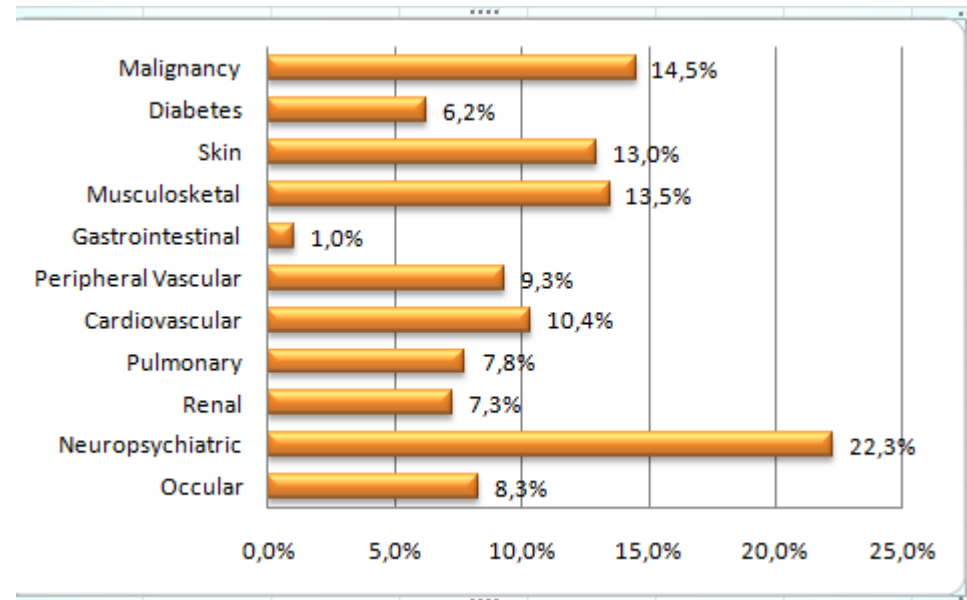
Non reversible damage



Transition rates (2012 -2015)

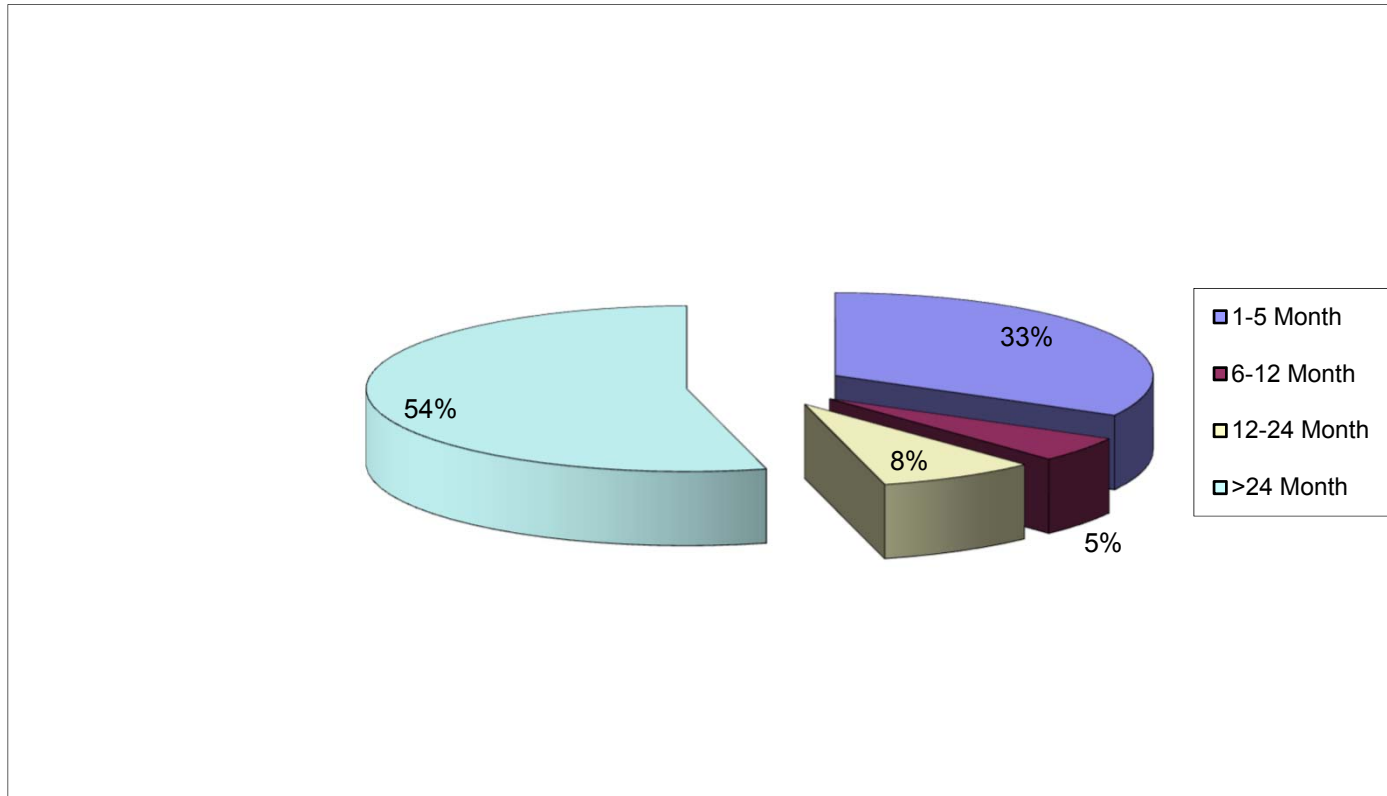
SDI 0 → SDI > 0 : 8.2%

SDI >0 → SDI + : 2.4%



***37,4 % had accrued damage
in Leto Registry
(n=608)**

Is SLE diagnosed early?



Time from first symptoms to diagnosis.

*n=196 (patients questionnaires
Leto Registry)